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ABSTRACT

The effects of New Hampshire's guardianship law on other disciplines in dealings with disabled persons are examined. Transdisciplinary efforts to promote more normalizing methods of protection are noted, and the bias underlying many service systems (that disabled persons do not have a right to make wrong choices) is exposed. A multi-layered advocacy system is proposed, which spread across case management, physician, lawyer, service specialists, friends, educators, and therapists, promotes the rights of the impaired through shared perceptions and involvement. It offers protection, without stultifying growth. Among impacts noted are trends toward changing the requirements for annual bureaucratic physicals, increased cooperation among team members, increased emphasis by psychologists on functional abilities, and changes in attitudes toward risk taking and pursuit of less restrictive options. Recommendations address such areas as statewide training and dissipation of the myth that the severely impaired need total guardianship. (CL)

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AAMD Annual Meeting
Guardianship Reconsidered
Monday, May 28, 1984
10:30 a.m. - 12:00 noon

Jean Arrain

The Impact of New Hampshire Guardianship Law on Other Disciplines

Despite the gains made through state plans for deinstitutionalization, despite public laws 94-103, 93-112, 94-142, the status of the developmentally impaired in this country continues to be that of an underclass - or minority. For those legally of age, true adult status is far from a reality.

New Hampshire's Action for Independence, its historic lawsuit, (Garrity vs. Gallen - now Sununu), its RSA:171-A which defines placement in the service system - and - Chapter 464:A - Guardianship and Conservators - are all monumental efforts to restore human rights - to reverse the minority status of our impaired citizenry. And, in keeping with these efforts, the Executive Committee of the AAMD Northeast, Region X included support of due process protections and limited forms of guardianship among its annual legislative goals in October of 1983. However, nationwide to date, only 28 states include provisions for limited guardianship. As of 1979, 33 states retained plenary guardianship statutes.

Because his leadership has informed so much of what case managers do, we speak in Wolfensbergian terms. In his terms, in New Hampshire - and nationally - we continue to witness the rejection of the disabled. We continue to witness, but not support their lack of autonomy. Yes, even as state and nation, we have made substantial gain. Sometimes, we even acquiesce to their exclusion from our own value systems. To promote any form of inappropriate control or any mechanisim of ov[illegible]rotection is to devalue the impaired.

To question methods of protection for documented areas of need, is to explore the extent to which a person's right to participate in that protection will be insured.

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It is a central aspect of our role as case managers to educate the enabling and treatment professions: social work, psychology, medicine, law, teaching, that protection of rights and freedoms is the focus in guardianship issues. What parents see as proprietary rights for themselves often makes for conflict with other positions in treatment disciplines which clarify the rights of age-emancipated offspring.

To this end, 464 can be viewed as an attempt to reduce the ambiguity inherent in antiquated guardianship statutes. 464 addresses issues such as: "How do we protect rights by taking them away?" - or "How do we promote growth if we insist on substitute decision making for every aspect of an individual's life?"

To grapple with the institutionalized ideation of guardianship is to come to terms with the forces in our culture which made the barbarism of institutionalization a possibility: the forces which remove rights, which imply deviancy, sometimes criminality, ultimately punishment - or - e.g., one may leave the institution but be denied his adult right to freedom of choice by his parent-guardian. One may clearly benefit from his day or social program, but find the parent-guardian at odds with the program directors. And All states can point to numerous instances of the termination of day programs for the adult impaired, because the parent, as guardian, fears relinquishment or loss of control. We can cite history after history where the triumvirate: physician, school nurse, probate judge, pronounced sentence to "enable" parents or relatives, as guardians, to route their offspring or siblings to the state training school or the institution for "mental defectives".

From this historical perspective, most states, until the last 10 years, outside of enlightened government commissions and professional and advocacy

groups did not even question the fact that guardianship gave almost total authority to the guardian to determine whether or not the disabled lived in or out of institutions, that guardianship defined service. Our institutions and their "service" systems testify to the competence and commitment of that guardian-authority. And the maelstrom created by our failure to address this issue early in the history of deinstitutionalization will persist for decades.

However, on the positive side, now - New Hampshire, as well as other states, is beginning to observe the outcomes of trans-disciplinary efforts to sustain more normalizing methods of protection for the impaired. And, in this rigorous preoccupation with normalization - lately - "social role valorization" - we have begun to look at our presumably less deviant selves for answers to necessary questions: when do we defer to our guardians in matters of money, housing, vacations, treatment, choice of clothes, et al?

We have begun to scrutinize the bias which has characterized our service systems on a national basis: that the impaired because of their disability do not have a right to make wrong choices. We are not comforted by our wrong choices: pollution, nukes, crime, decay of cities, decline of schools.

And - we do not necessarily buy the idea that court-appointed guardians are more committed, more caring, less self serving, than friend advocates - conservators, professionals willing to share time and expertise. We do observe that guardians will be better educated if they are limited in their perogatives, if they are kept informed about major concerns.

This multi-layered advocacy system spread across case management, family physician, lawyer, service specialists, friends, educators, therapists,

operates to promote the rights of the impaired through shared perceptions and involvement. It offers protection, without stultifying growth. It is the classic system of checks and balances; it requires a central coordinating effort such as case management. Integrative in nature the citizen group is more accountable to the client - and - each other - than any one citizen to the court.

The outcomes submitted here derive from participation in many guardianship issues over four years time as a case manager and coordinator for human service programs for over a hundred clients from 1977-1984. More narrowly, the outcomes are partially the result of a project initiated three and a half years ago by Case Management on behalf of four-six moderately to severely retarded people. Their institutional experience ranged from 1 - 47 years. Data is based on observation of client behavior, primary and secondary data from ISP providers, one-to-one and team interaction with the client, and evaluation and remediation of treatment, training and professional ethics.

Outcomes - impact statements about the legal community's response to this change in doing business range from initial resistance, three and a half years ago, and outright lack of familiarity with 464, to current observable changes more subtle, but powerful, - From judges and lawyers' comments in and out of hearings: "Anyone can see he's retarded", to the now more prevalent exchange with the service team about the functional abilities and anticipated gains for the client, some community lawyers outside the D.D. Advocacy Center now exhibit interest in treatment versus containment. They invest in the self-actualizing aspect of risk. It would be romantic to suggest universality, however; - recently a lawyer representing a young client of mine, subsequent to a CHINS petition, asserted that his role as guardian

ad leitem was to facilitate the interaction of agencies in service to his client as protection for her individual service plan. That would have been a fine role to play if the system had not exhausted its services. Here the lack of advocacy for the client to be served outside of the juvenile detention system resulted in temporary reinstitutionalization. This lawyer's temporary guardianship role could have helped to stimulate the creation of appropriate services for our mutual client.

While the medical community in its concerns about malpractice continues to order up an array of diagnostic procedures, it is simultaneously willing to acknowledge that clients can be healthy. Some physicians suggest changing the annual bureaucratic physical to something more reasonable like an exam every two years for the "healthy" impaired. Imagine the saving in Medicaid dollars and in coordination time. Imagine the change in perception from ill to healthy and its spin-off effects throughout the system! Now trust is often given over to service providers for health maintainence, when it is an issue.

Team consultations with neurologists have been unusually productive. For one client whose retardation is complicated by a twenty-three year history of self abuse, an esoteric neurological disorder, and tardive dysknesia, as well as bouts with psychotic states, two neurologists have accomodated team information based on outcomes of behavioral programming; they have readily adjusted dosages, reviewed articles by consultants from other disciplines, explored medications from other countries.

The guardian, in this case, limited by the court to act in cases of medical emergency, has yet to be consulted since his appointment two years ago! Clearly, the position of these physicians has been to work with the team and the client to a point in treatment when it will be feasible to withdraw medication entirely. The client, whose behavior has been typically

out of control for over twenty-one years, who had had no service system until age twenty-three, is now working part-time in Work Activities. He converses rationally with his doctor. He also jogs, throws a basketball backwards, and has begun to develop peer relationships. Until this year, he saw himself as a young child. He was labeled severely retarded. While he still has many deficits, his gains promise additional accomplishment.

Ruth - A community client. Ruth's opthalmologist refused to consider removing cataracts on both her eyes. His note referred to her retardation and his lack of expectancy of any kind of progress. She was fifty-one. Conversely, Ruth's second-opinion opthalmologist recommended an intra-ocular implant. He had successfully performed this procedure on over one hundred clients during the experimental period. Since Ruth did not have a guardian, the team chose not to petition. Relatives, case manager, day program providers and physician chose to share the risk. Ruth signed the informed consent and we co-signed with her. That was in 1982. Within six months, Ruth had achieved normal vision in the implanted eye and is considering having a second cataract removed. Now she works on activities that demand eye-hand coordination that previously she could not do. No fear of mal practice suits here. And total understanding of the dignity of risk by her physician.

Social work, as it plays out in the Division of Welfare, makes no pretense about its support of total guardianship. It is the bureaucratic machinery which obscures issues of rights. Here the central concern is accountability to the system itself - hardly the client. From refusal to pay court appointed, limited guardians because the (D.O.W.) budget did not "include" our clients to the active bias that disabled clients are incapable of any decision making, the war against the D.D. system goes on. If there is any gain, it is that social workers now, sometimes, address clients by

name in the initial interview. If D.O.W. social workers appear at guardianship hearings at all, their focus continues to be regulatory.

In criticism of the tyranny of testing, psychologists are at their best in reporting - and testimony - when their data focuses on functional abilities. They have given up, generally, the references to "classic testbook cases" and what this or that textbook case of retardation or disability can be expected to do. It is the positive, growth producing attention to describing what a client can do, now and might reasonably gain, with appropriate services, rather than the preoccupation with finite I.Q. scores which helps the psychological community take its place in promoting rights, risk, treatment.

Even when the court hearing or the ISP process comes to terms with the extent to which disability impairs ability to make decisions, there is visible cognition about client's rights to take action, be given information and treatment - or to reject it. Lawyers for the petition are much less adversarial, in the traditional court sense, that decision making power should be transferred to another individual. They are more willing to be instructed.

What the players in the court arena are getting very good at is seeing that the impaired do have as much right to make decisions and be wrong as those of us less impaired. And the court is much more concerned about the deprivation of freedom, now explored in Probate encounters.

As paraprofessionals, residential educators and trainers are making among the most significant contributions to the limiting of guardianship. Because treatment-training is what they do, they are in a position to promote the rights protected by the court limitation of guardianship parameters. On-site educators interact with the guardian as mutual team members, according to the ISP and in the spirit of 464. The functional authority of the service team is sanctioned without continual recourse to an absentee authority. This

reduces staff-guardian control issues and maintains the focus on client growth.

Another client, Dorothy, institutionalized for forty-four years and formerly seen as medically fragile, and whose institutional petition for full guardianship got "lost" in the "coming out" shuffle, has shown incredible progress. Soiling has been eliminated through behavioral training. Immobile for years, she is now physically active. I watch her use an exercise bike every week. The preoccupation with health exams which seemed to call for a guardian for medical emergencies has ended. Dorothy's language has developed into complex sentences. She bears no resemblance to the almost mute, often ill and constantly probed and examined "inmate" of four years ago. It may be appropriate now to petition to remove even this limited form of what is only paper protection.

In summary, this is the impact of 464 on other disciplines in New Hampshire:

1. Personhood, client centeredness is beginning to be acknowledged by the courts;
2. Team process has been legitimized by the Probate Court proceding;
3. The interaction of relevant client treatment disciplines is less power oriented - more process centered;
4. Treatment modalities are explored as alternatives to full guardianship;
5. Perceptions of the impaired as more normal adults are made viable, through 464;
6. Functional attributes are highlighted. There is less focus on deficits and impairment. We hear fewer comments such as "he's a Downs", or a "Gloid", or "she's autistic" - labeling is decreasing;
7. Attitudes are subtly altered toward risk taking and pursuit of least restriction;

8. 464 addresses inappropriate treatment: i.e., psychosurgery, electric shock, sterilization, experimentation. See 464-A:25 (C).

Recommendations

This project initially focused on four to six severely disabled clients, not only to serve them appropriately, but to actively examine the bias that it is the severely impaired that need total guardianship. Dissipation of that myth is inherent in such programs as the Oregon model, STEP which places the severely disabled in productive work programs instead of locking them into medical model, day habilitation, therapy-oriented centers. Without protective mechanisms which are suitable to a model such as this, it is possible that the freedoms of its participants may be restricted.

Nationally, we need to confront a planning step hiatus. It does not make sense for state planners and legislators to follow federal law with action plans for deinstitutionalization without initially upgrading the implementation steps which follow guardianship law reform. Somehow, many of our clients found themselves in the community through offices of public guardianship, accompanied by total guardianship - a perpetuation of the idee fixe of dependency. Or parents brought them out of institutions and maintained parent rights - more appropriate to children.

Our way out of this maelstrom is to, early on, establish training to deal with the whole matter of protection - on a stepped up state-wide basis. Some regions are beginning to do this. It is a basic piece in state service system planning which can result in normalized individual treatment. We are now dealing with the issue reactively and the "Tar Baby" gets stickier.

Within the Individual Service Plan meeting, review of guardianship can be more appropriately placed nearer measures of strength rather than at the

end of goals and objectives. If a client has a number of need areas, providers can be trapped into assuming that this implies full guardianship.

Additionally, the limited guardian as provider, needs to be trained for his role rather than supported as a dispenser of arbitrary and binding decisions. Protection, wherever possible, should be sought outside the courtroom in informal agreements among providers. The courtroom process is financially burdensome to society and demeaning to our clients.

State planning agencies and councils need to dialogue in open sessions involving O.P.G. and case managers and the region-community as to their overlapping areas of concern - and their conflicts of interest.

At least one region in New Hampshire now utilizes the services of a paid DMHDS consultant to work through protective issues. If consultants are used, then decisions, findings, ought to be communicated to all regions, through small demonstration projects. To address protective issues four years or ten years into deinstitutionalization is possibly to have truncated the quality of life for those who have that long lived in our communities.

In response to these issues, California has enacted a law to end total guardianship. For a discussion of this see the reference in the bibliography for Apolloni and Cooke.

Massachusetts has developed a "Committee" of impaired citizens to halt formal attempts to route the deinstitutionalized back to Belchertown - its state institution.

And through what we do here in AAMD resolutions, we can continue to enable other states to review their commitment to over protection - to examine its disabling quality - states could truly carry out the mandate of the Developmental Disabilities Assistance Act in a fashion congruent with their own legislation and in the spirit of the Constitution.

Through this conference effort to address a primary area of struggle, case managers can assume a more enlightened posture, as hand maidens to subsequent history - a history notable for its dignity toward this minority.

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Annotated Bibliography

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Guardianship and Conservatorship. A Statutory Survey. Developmental Disabilities State Legislative Project of the American Bar Commission on the Mentally Disabled. June 1979. See p. 75 for model statute which attempts to alleviate inequities and anachronisms of plenary guardianship.

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One among a collection of articles which emphasizes the citizenhood of impaired people, in relation to basic freedoms, rights.

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